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# **Young, single and treated for breast cancer: making sense of my sexuality**

## **An exploration of women's stories**

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For the Degree of Master of Arts (Clinical Counselling)  
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Clinical Counselling  
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## **Abstract**

This qualitative study explores the experiences of four young, single women, who were diagnosed with breast cancer, and examines the impact of this on their sexuality, during and post-treatment. The data was gathered using semi-structured interviews, and analysed using Interpretative Phenomenological Analysis (IPA). Emerging themes included identity loss during treatment, differing degrees of adjustment to an altered body post-treatment, and concerns around dating and new relationships. Although each participant was clearly moving forward in positive ways, ongoing emotional losses were also described, including those related to fertility. Findings largely support earlier work in this area, although there have been very few studies with this particular sub-group of women. One finding that differed from other research was the universal acceptance by prospective partners of participants' altered bodies.

## **Declaration**

This work is original and has not been submitted previously in support of any qualification or course.

**Signed:**

SUSAN SHORTT

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## **List of Abbreviations**

BACP - British Association for Counselling and Psychotherapy

BCC - Breast Cancer Care

IPA – Interpretative Phenomenological Analysis

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# 1. INTRODUCTION

*'I would never have chosen this path,  
but I am very glad to be  
who I am, here'  
(Lorde, 1980)*

## 1.1 About the Researcher

My interest in the stories of young, single women treated for breast cancer originates in my personal experience of being a member of this group. Eight years ago, I was diagnosed, in my 30's, with breast cancer, and embarked on an intensive and lengthy treatment path. The experience has undoubtedly impacted on my identity in many ways, some extremely positive and growthful, "a wake-up call" (Gorman 2011); but some much more painful and difficult. A breast cancer diagnosis as a young woman was described by one child-free woman as changing the entire trajectory of her life (Gould et al. 2006); this resonates.

At a counselling course residential, I found myself exploring, in front of the group, my narrative of before, during and after treatment, in response to an invitation to consider influences on our sexuality. I had not talked through the chronology of my journey in this way before, and having this witnessed by my peers felt very powerful and affirming, and hugely emotional. It also caused me to reflect upon how this area had been one of the hardest aspects of my diagnosis, and one that is seldom talked about, both in clinical settings and amongst friends. The ending of a relationship during my treatment, and the subsequent search for a new partner, brought to the fore a raft of issues, both physical and psychological, that I was completely unprepared for.

There was a sense of me having to re-write the narrative of my life to accommodate this “off-time” event (Wurm et al. 2008), and I began to become interested in how major illness interrupts the predictable course of life and forces us to write a new story (Neimeyer et al. 2002; Frank 1995).

I volunteer for Breast Cancer Care’s (BCC) ‘Someone Like Me’ service, offering support to women following diagnosis. Hearing other young women’s stories and struggles in relation to their sexuality, also fuelled my desire to explore this area. At young women’s events, optional sessions on sexuality and intimacy are popular, and people appear relieved to have found a forum to share their concerns. But along with much of the information literature I have come across, it is often the case that sessions such as these very much refer to ‘you and your partner’, leaving single women isolated. And so, the strands of my research topic took shape, to encompass a breast cancer diagnosis along with being younger, being single and examining the impact on sexuality. I acknowledge that in embarking on this research, as well as wanting to bring the experiences of this group to a wider audience, it may prove to be an important part of my own personal journey.

## **1.2 Rationale**

As I began to look for existing research, I discovered little about this topic focussed on this group. This made it feel all the more important, and I would like in some small way to begin to redress the balance. There are distinct issues faced by young single women who have experienced breast cancer (Gluhoski et al. 1998), for example in the area of dating. I would like to enable some of these women to have their voices heard, and by doing so broaden awareness amongst the counselling community of this group, and give a flavour of their experiences. I would also like to contribute to the “pedagogy of suffering” (Frank 1995, p.145); this posits that someone who suffers

has something to teach, and therefore has something to give, thus restoring agency to the ill person and giving their story parity with professional expertise. As Adams et al. (2011) note, a quarter of all cancers in adults under 45 are breast cancers and it is the most common type of cancer for this group. It is therefore likely that counsellors may encounter younger women who have faced this diagnosis.

### **1.3 Aims and Objectives**

My research question was:

‘What is the impact of breast cancer on the sexuality of young, single women?’

My aims were:

- To explore the sexuality narratives of young, single women, before, during and after treatment. My main focus was on during and after, with before providing context and comparison.
- To ‘get under the skin’ of what it had felt like to live through this experience for young, single women, and the adjustments to narratives that may have been made during this

I wanted to allow a wide-ranging discussion, and whilst I did not present participants with a definition, I provided a list of areas that sexuality may encompass, based on my thoughts, and areas covered in existing literature. These included body image, dating and relationships, libido (sex drive), early menopause and fertility. I invited them to consider these, and any others they wished to; it felt important to give participants the freedom to include aspects important to them.

## **1.4 Overview**

The remainder of this dissertation is structured as follows: in Chapter 2 I provide a review of relevant literature, and situate my research within this. Chapter 3 describes the methodology used and rationale for this. In Chapter 4 I present my findings; Chapter 5 discusses these, in the context of existing literature, and in Chapter 6 I offer my conclusions.

## **2. LITERATURE REVIEW**

### **2.1 Introduction**

A systematic search and critical reading of literature on my research topic was essential to my study making any kind of contribution to the body of knowledge (Hart 1998). My search criteria are detailed in Appendix 1. I made extensive use of online journal and e-book resources from Chester and Liverpool Universities, and also utilised Google scholar, websites and information booklets, together with books from the library, and purchased.

My literature review was largely conducted prior to data collection, as it was a cornerstone of my research proposal. This groundwork helped me to identify a gap that my research question would address (Smith et al. 2009). I adopted a thematic approach to the review (McLeod 2003), and present this below, preceded by a brief summary of the overall context in which my study sits.

It soon became clear, that like-for-like comparisons of studies would be difficult, as the diversity in sample type (e.g. age group, time since diagnosis) and methodologies employed was so great. As there are several 'strands' to my research, I present a limited amount of literature for each element; this is the result of a sifting process to try to find a fair representation of what has been written thus far; inevitably there is some overlap between categories. The synthesis presents evidence that this new piece of research is required and of significance (Fink 2010).

### **2.2 Background**

Each year, around 55,000 people in the UK are diagnosed with breast cancer (BCC 2014). This includes around 350 men, but this research focuses on women. There are around 9,800 cases each year in women under 50, and very few of these occur

in women in their teens or early 20s. Breast cancer is however the most common cancer in women aged under 40, and in women aged 35-39 in the UK, around 1,300 cases of breast cancer are diagnosed each year (Cancer Research UK, 2014). These statistics position a breast cancer diagnosis as a young woman as an unexpected and relatively rare event.

Very few published studies on younger women's experiences of breast cancer conducted in the UK exist; notable exceptions are Corney et al. (2014), and Adams et al.'s (2011) synthesis of the work of others. Corney's work is primarily concerned with fertility issues, although it did also consider partnership issues. Many studies have a medical slant, and aim to provide information to healthcare professionals about how they might best support patients (e.g. Gould et al. 2006; Thewes et al. 2004; Takahashi 2013; Kissane et al. 2004; Ganz 2008). Some research is written in very medicalised language (e.g. Cardoso et al. 2012). Gould et al.'s study was large by qualitative standards, and included 65 young women in 10 focus groups. Whilst its emphasis was very much on support and information needs, this did draw out some of the themes pertinent to younger women, including the unexpected side-effects of treatments on sexuality.

There is an abundance of quantitative studies, (e.g. Fobair et al. 2006; Fallbjork et al. 2013; Burwell et al. 2006; Avis et al. 2004; Meyerowitz et al. 1999). Avis et al, in their study of over 200 women do include some open ended questions, and note that responses to these were particularly informative, acknowledging that purely quantitative studies obscure the diversity of experiences. Far less, however has been written about the qualitative lived-experience. Adams et al. (2011), in their meta-ethnography found just 17 qualitative studies, conducted over a 20 year period, that focused on the experiences, needs and concerns of younger women with breast



cancer. Coyne & Borbasi's (2006) study is noteworthy from a methodological perspective, with its emphasis on enabling women to tell the story of their journey, without the rigidity of set questions, adopting a feminist approach to the encounter. Her aim was to give health professionals a greater understanding, and her ethos resonates with mine.

## **2.3 Young**

This quote from a participant in a further study by Coyne & Borbasi (2009) gives a flavour of the impact of a breast cancer diagnosis at a young age:

“...in one fell swoop I was told everything that was feminine about me was gone, I was losing my breast, I possibly couldn't have children. ... all of a sudden choices for the life I had planned were being taken away from me” (p.10).

Young women can feel marginalised and isolated as they do not conform to the 'normal' older profile of a woman with breast cancer (Dunn & Steginga 2000), and as a distinct population, they are an under-researched group in terms of specific key issues and concerns they face (Adams et al. 2011).

A recent review of 28 large scale, quantitative studies conducted over a 15 year period amongst women under 51 or premenopausal at diagnosis, found that compared to older women diagnosed, and the normal population, younger women experienced some reduction in their quality of life, with a greater impact on emotional well-being than physical functioning. Main anxieties were around fear of recurrence and what may happen in the future. Depressive symptoms were relatively common, and menopausal symptoms, such as hot flushes, lack of libido and vaginal dryness were a source of concern for many, as were fertility issues (Howard-Anderson et al.

2012). Whilst this review provides some useful pointers as to areas that may cause difficulty, it does not address the lived experience of these women, and a more qualitative approach is required to uncover this.

A comprehensive review of qualitative research amongst younger women identified feeling 'out of sync' as the issue that 'permeates all others'; breast cancer is a disruption to the normal life-course (Adams et al. 2011). There are clear links here with theories about 'assumptive worlds' (Parkes 2009); each person has an internal model that they assume to be true; it contains everything we take for granted, and when an event occurs to disrupt this, we become lost. Reproduction, body image, fear and sexual activity are also identified as key issues in Adams et al.'s review. From this, the authors construct an interesting conceptual model suggesting how women experience and respond. They propose three processes, used in varying combinations. The first is balancing, for instance balancing the immediate priority of treatment with learning to adjust to sudden menopause, or weighing up desire for a child against future health concerns. Next comes normalising; this may be by having reconstruction to re-gain a sense of normality, or for some by normalising an 'imperfect' body. Lastly, changing is identified as a process, often part of a wish to find a new 'normal', and this can comprise both negative and positive elements. For example, infertility may force a change in plans for a family. On a more positive note cancer may be perceived as a turning point, and lead to better self-care or new activities. As with all 'meta' research, the authors are distanced from the original data, and findings are generalised, but this study does provide a rare and useful insight into issues specific to younger women and draw these together into a model that illustrates the complexity and fluidity of response to diagnosis. Its validity is demonstrated for example, in the work of Kirkman et al. (2014), whose participants describe balancing the need to stay alive with their desire to have a child.

## 2.4 Sexuality

Until recently, research examining the impact of a breast cancer diagnosis on sexuality mainly took place within the context of a positivist-realist paradigm, and was focused on the physical aspects of women's experience, and satisfaction or dysfunction in their sexual relationships (Emilee et al. 2010). However, women do not equate how often they have sex with sexual satisfaction. "Their sexuality is much more complex, involving issues of self-esteem, identity, body image, and role functioning" (Wilmoth 2001 p279). Her study asked women to define what sexuality meant to them, and the impact breast cancer had on this part of their lives. Whilst her participants were mostly over 45, the resulting themes of missing parts, loss of womanhood, loss of bleeding, and loss of sexual sensation would appear pertinent to younger women too. These combine to form an 'altered sexual self'. The supportiveness of partners, and the degree to which women took control of finding out information relevant to their treatment appeared important in how women adapted. Wilmoth proposed three processes; *taking in* the diagnosis and changes to the body, *taking hold* of the losses and coming to terms with them, and those who were managed to do this, moved on to *taking on* the role of breast cancer survivor and gaining some control over treatment side-effects. Her study explores menopause in some depth which is not relevant to all participants in this study. Wilmoth's grounded theory model conveys well a sense of movement and agency for the women. It does however feel a little prescribed, but could be considered as a useful framework of elements and processes that may be experienced, and valuably highlights the sense of loss experienced.

Prior to Wilmoth's study, a dissertation by Turner (1999) also pioneered a more women-centred approach, in inviting women to explore the impact of their diagnosis

on sexuality, using their own definitions. This provided vivid quotes of their lived experiences and chimed with my aims to 'get under the skin' of what a breast cancer diagnosis meant for my participants. It did not however focus specifically on younger women, no participants were single, and just one was childless. It does provide an early example of challenging a narrow definition of sexuality, and her model of a 'reconstructed sexual self' is sociological, considering a wide range of influences. In considering sexuality in this way, it does lose its connection to individual women's stories at times.

Few studies have focused on younger women in relation to body image (Rosenberg et al. 2013), and those that do, tend to look at short term rather than longer term impacts, and are quantitative (e.g. Rosenberg et al. 2013; Fobair et al. 2006). Fallbjork et al. (2013) did follow up women almost 3 years post-surgery, and illustrate the difficulties in matching such a nuanced and personal subject with a quantitative methodology. They discovered a decrease in feelings of sexual attractiveness and comfort over time, and spent much of the discussion speculating as to why this was the case; a sensitive piece of qualitative research may have revealed some answers.

Some research indicates that breast conserving surgery (lumpectomy) has less impact on body image than mastectomy, with or without reconstruction (Rosenberg et al. 2013; Kissane et al. 2004). A review by Emilee et al. (2010) notes that overall results are mixed as to the impact of differing types of surgery on sexuality (of which body image is a part). Varying methodologies and samples make robust comparisons difficult, and I would argue there are multiple variables that come into play, for instance body image prior to diagnosis, reaction of partner. It has been suggested that greater than the impact of type of surgery on sexuality, is that of the chemotherapy and hormonal treatments that many women undergo Klaeson et al.

(2011). Chemotherapy is associated with increased risk of sexual difficulties (Avis et al. 2004), and for younger women the combination of sudden menopause, and associated symptoms such as vaginal dryness, loss of sexual function and loss of fertility can be particularly devastating (Ganz 1998). Archibald et al.'s (2006) qualitative study, whilst narrow in its focus on sexual functioning following chemically induced menopause, does give some insights into the lived experience, missed by quantitative studies. For example, one single young woman is quoted, wondering how any young man will handle her lack of sex drive and a body that she now perceives as old.

Chemotherapy induced hair loss can also be extremely distressing and pose a threat to body image (Power & Condon 2008). This is borne out by Thomas-Maclean's (2004) research on embodiment; a participant speaks of hair loss being so visible, and as such in some ways harder to cope with than breast loss, and a participant in Hefferon's (2008) thesis echoes this, describing her hair loss as worse than losing her breast.

Larder (2010) notes in a BCC qualitative study on body image, that for many of her respondents, whilst there was a degree of adjustment, the effects of breast surgery stayed with them, and as a result they never became fully accepting of their body image. One, ten years post-diagnosis, talks of learning to accept her mastectomy, but still hating it and feeling it looks ridiculous. An interesting counterpoint to studies suggesting ongoing difficulties with body image can be found in the research of Dunn & Steginga (2000), who asked participants to 'vote' on a list of words as to

which best reflected their breast cancer experience. 'Unattractive' was only chosen by 3 out of 21 women.<sup>1</sup>

## **2.5 Single**

There is a paucity of research specifically examining the experiences of women who are single at some point following their breast cancer diagnosis. More commonly, brief comment is made about this group, as part of a larger sample (Schover 1991; Dunn & Steginga 2000; Thewes et al. 2004; Gould et al. 2006; Archibald et al. 2006), or no mention is given to singles at all (Cardoso et al. 2012; Cebeci et al. 2010; Emilee et al. 2010).

It is acknowledged that seeking new relationships after breast cancer can be a specific stressor for younger, single women (Schover 1994). Often cited is a qualitative study by Gluhoski et al. (1998), amongst a sample of unmarried women as part of a study about pregnancy post breast cancer; all women believed they were still fertile. As such, it does not address fertility concerns, but does identify a set of unique stressors for unmarried women: pessimism about future relationships, fears about disclosing illness to partners, negative body image and impaired sexuality, pain of rejection by partners, and a sense of isolation and inadequate support. A sense of anxiety around dating, broaching the subject of cancer, fear of rejection and being found sexually undesirable, and never being able to form a new intimate relationship is echoed in the work of Holmberg et al. (2001). Feelings of being a liability to a future partner if the cancer recurs can be another fear (Thewes et al. 2004).

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<sup>1</sup>See BCC website, 'A letter to my body' (<https://www.breastcancercare.org.uk/whats-your-experience>) for an insight into the range of responses experienced in relation to body image post breast cancer.

An anecdote from a participant (Wilmoth 2001) felt particularly discouraging. She told a man she was starting to date that she had breast cancer, and then went to the kitchen to pour drinks. When she came back, he had left. This caused her to completely avoid dating and male company. There is not much written about experiences when people did start to date, and this something I would like to redress a little with this study. An early piece of research that does include this, is a dissertation by Whitney (1988), from a feminist perspective, who interviewed single lesbian and heterosexual women about the impact of breast cancer on their 'sexual scripts.' It is notable for its qualitative approach, treating each participant as an individual case study initially and conveying a rich sense of their varied experiences.

More recently, Corney et al. (2014), as part of a study concerning fertility, interviewed young, single women, and similarly noted fear of rejection by potential partners, together with dilemmas around having children, and limited options for fertility treatment as some of the key issues they faced. With regard to infertility and loss of choice about having children, women believe that these concerns can sometimes be trivialised by health professionals, who feel that they should be more concerned about survival than loss of fertility (Dunn & Steginga 2000).

An "utter silence" is described by young single women with breast cancer, surrounding understanding of sexual changes in their bodies and how to feel sexual again with a new partner (Gould et al. 2006). There is not much support information specifically tailored to this group. Several years ago, I contributed quotes to a BCC publication entitled 'Sexuality, intimacy and breast cancer', but looking through this and other similar publications, there is generally just a paragraph about being single, with most of the information geared towards those in a relationship. A brief look at other on-line resources resulted in finding an informative page on the American

Cancer Society website devoted to the single woman and cancer, and on the Stanford Medicine website, a doctor states that it is rare to come across anything geared to young, single, women, and she blogs about dating tips. Interestingly, as far back as 1991, Schover was suggesting that being young and not in a committed relationship were 'risk factors' that the healthcare team should be alert to, suggesting that this group may benefit from brief counselling, hearing about other women who have found new relationships post-cancer, and help in planning how to date again and when to disclose their illness.

## **2.6 Illness Narratives**

Narrative-knowing provides a means of integrating the strange and unknown into the realm of everyday life (Murray 2003). Neimeyer et al. (2002), taking a constructivist, narrative approach to their work around meaning reconstruction, write of major losses challenging our understanding of the previously adequate narratives of our life, and of the requirement to develop new ones. They call this 'narrative repair', and see the goal not so much as a final truth, but an account where things can seem meaningful once again. This seems pertinent to young women's accounts of breast cancer.

Frank's (1995) seminal work views illness as resulting in a narrative wreck: "The illness story is wrecked because its present is not what the past was supposed to lead up to, and the future is scarcely thinkable" (p55). He goes on to identify three types of illness narrative - restitution, which is based on a return to health, chaos, in which it is imagined life will never get better, and quest, in which the illness is accepted and the person looks to use it positively. He discusses these in the sociological and political context of the medical profession and wider society. His



comment that there is a need for clinical staff to witness the chaos rather than try and drag the patient out of it resonates with the values of person-centred counselling.

Bertero & Wilmoth (2007), in a meta-synthesis of qualitative research on breast cancer treatments affecting the Self, make reference to Frank's quest narrative. They write of a process of redefinition of the Self, that includes women reflexively questioning their sense of womanhood in the aftermath of treatment. Whilst this is a valuable concept, their methodology is several steps removed from original data, and as such their findings are very generalised.

Broyard (1992), writing eloquently of his terminal cancer, also suggests storytelling as a natural response to becoming ill; in a crisis we invent a narrative. He also speaks of developing a 'style' for his illness and the importance of this in the face of the illness diminishing his sense of self. Whilst this is clearly a very personal piece of writing based on his experiences it does illustrate well the loss of identity in illness.

## **2.7 Conclusion**

This chapter has provided a summary of some of the key research to date and the themes that have emerged, and situated my study in context. Whilst there are many quantitative studies that do highlight particular issues, there is less qualitative research, and very little conducted in the UK. I believe I have identified a gap to address (Smith et al. 2009), in inviting my participants to tell their story of the impact of a breast cancer diagnosis on their sexuality as young, single women, and to reflect on this, several years on.

### **3. METHODOLOGY**

#### **3.1 Research Philosophy and Design**

The choice of design for a piece of research is influenced by factors including the researcher's values, by philosophical considerations and the intended audience (McLeod 2003).

I begin from my position as a person-centred counsellor, with my intended audience, the counselling community. The Person-Centred model has its roots in phenomenology (Merry 2002); a branch of philosophy developed by Husserl in the late 19<sup>th</sup> century. Phenomenology aims to describe the essence of everyday experience, and involves laying aside existing beliefs to reduce the phenomena under investigation to its essential qualities (McLeod 2011).

Qualitative research sits under the phenomenology umbrella, and has as its focus an understanding of the meaning events have for the people being studied (Maykut & Morehouse 1994). Its emergence can be traced back to a reaction against the prevalent positivist paradigm of the late 19<sup>th</sup> and early 20<sup>th</sup> centuries; this emphasises objective observation, quantifiable data and verifiable truths, and uses statistical analysis (Mintz 2010). Lincoln and Guba's (1985) seminal work provides a useful comparison of the axioms of a positivist and a post-positivist qualitative paradigm. They comment that "positivism has produced research with human respondents that ignores their humanness...." (p.27); for me, this encapsulates the argument against using quantitative methods in this study.

I am a member of the group that I am researching, and being open about this, both with participants and readers felt "a moral and ethical approach." (Etherington 2004, p.22). Self-awareness is required, to disclose ourselves to others, and this

awareness enhances our perceptions and observations, and helps us to recognise that there is ambiguity and possibilities in participants' stories. (Etherington 2001). This links with the work of earlier feminist authors who write of 'conscious partiality' and the researcher's willingness to be known by and identify with the participant. (e.g. Mies, 1983; Oakley 1981). Whilst this approach, with its sense of co-operation, sisterhood and sharing of power was intrinsically appealing, it felt 'safer' as a novice researcher to use a more traditional interviewer-participant structure, whilst allowing myself to be known and seen as a member of the group. That said, I did experience a strong sense of 'sisterhood', and occasionally shared small pieces of my experience when it felt appropriate.

A challenge throughout has been the phenomenological concept of 'epoche' or bracketing off my existing assumptions to view the world afresh, a perhaps paradoxical position of 'indwelling', whilst simultaneously being aware of the influence of one's own biases (Maykut & Morehouse 1994). I was however, encouraged to read that Heidigger, in his work on hermeneutics (the theory of interpretation) portrayed a lively, cyclical interplay between the researcher's pre-conceptions and participants' experiences, and an acceptance that bracketing can only be partially achieved (Smith et al. 2009).

Reflexivity is key to ensuring a critical awareness of our assumptions (McLeod 2011). Throughout my research I have sought to approach my interviews with an open mind, not assuming that participants' experiences will mirror my own. McLeod (2003) cautions that in very personal studies the researcher may find it hard to stand back enough from their own experience to gain a sense of the bigger picture described by others. A reflexive journal has proved invaluable in this endeavour, as a place to note thoughts and feelings, and be open about aspects of myself that may be colouring

my research. It is inevitable that my work will be influenced by my experience, and in fact this feels valuable, with the caveat that I have sufficient self-awareness to understand this and am transparent about it - being reflexive is about being aware of our personal responses and being able to then choose how we use them (Etherington, 2004).

### **3.2 Sample**

Purposive sampling was employed to recruit my sample as I wished to interview members of a particular group (Smith et al. 2009).

Participants met the following criteria:

- Diagnosed with breast cancer at least 3 years ago
- Female
- Under 45 years old at point of breast cancer diagnosis, and over 18 years old
- Single (defined as not in a partner relationship) at some point since their breast cancer diagnosis
- BCC Volunteer or Service User
- Fluent in English
- Feel ready and able to take part and share their story

I volunteer with BCC, and asked if they would be willing to assist in recruiting participants. They have a range of support services in place; this reassured me that participants could access support easily if required, post-interview. They agreed, and I completed an application which was passed by their Service User Review Panel. My research advert (Appendix 2) was circulated by BCC through various channels, yielding one participant. The advert was revised into a less formal format after initial responses proved slow (Appendix 2a). This process did not yield sufficient interest. The remaining three potential participants resulted from an email from a BCC colleague to all 'Someone Like Me' volunteers who fitted my recruitment criteria. A

sample size of four is in the range recommended for an IPA project (Smith et al. 2009).

Each potential participant was sent an inclusion questionnaire (Appendix 3) and a participant information sheet (Appendix 4). All four expressions of interest resulted in interviews, and these represented a mix of ages and relationship and treatment profiles.

A week before the interview I sent copies of consent forms (Appendix 5) to participants to read in advance and an invitation to choose a pseudonym.

**Table 1 Participant Details**

| <b>Pseudonym</b> | <b>Age at diagnosis</b> | <b>Time since diagnosis</b> | <b>Relationship status since diagnosis</b> |
|------------------|-------------------------|-----------------------------|--|
| Ceri             | 38                      | 5.5 years                   | single, partnered                          |
| Jessica          | 32                      | 3 years                     | partnered, single, partnered               |
| Lizzie           | 23                      | 6.5 years                   | single, partnered                          |
| Sadie            | 34                      | 5.5 years                   | Single                                     |

(Further biographical information can be found in Appendix 11).

### **3.3 Data Collection**

Data collection in phenomenological studies tends to be via digitally recorded interviews, and for these to be relatively unstructured, to allow the participants to explore the areas they view as significant (Denscombe 2010). Semi-structured interviews are compatible with a variety of data analysis methods (Willig 2008), and this choice appeared a natural one; fitting well with the underlying philosophy of my research.

My interest in the way in which people make sense of experiences (Neimeyer et al. 2002; Frank 1995; Broyard 1992) influenced the design of my interview guide. My aim was to witness the stories of each participant, and in keeping with this 'narrative' focus, my interview guide was very unstructured (Appendix 6). A strength of this style of interview is that it gives the participant much more control in shaping what is explored (Murray 2003), but I was aware that in keeping the structure loose, it may be a particular challenge to keep the balance between remaining in control of the interview and where it goes, and giving the participant space to redefine the topic and generate new insights (Maykut & Morehouse 1994).

I recruited a friend, diagnosed with breast cancer when single, as a pilot participant; it is advisable to try out the interview with someone similar to the participant group (Spong 2011). This was helpful in checking the flow and in getting used to my role as interviewer, rather than counsellor. I was reassured that my relatively unstructured approach did encourage a free-flowing story of her journey. For some participants, the opportunity to speak in-depth about personal experiences can be very emotional (Murray 2003). This was the case for my interviewee, and a reminder of the sensitivity required in this research.

The interviews took place in a quiet and private location of the participant's choice (two at work, two at home). I had a lone working strategy in place for my safety. Before the start of each interview consent forms were signed (Appendix 5), and participants asked to provide their chosen pseudonym. Interviews were digitally recorded and ranged from 46-80 minutes.

Participants were invited to set the scene by briefly describing their breast cancer diagnosis and treatment, and then focussing on sexuality, asked to reflect on this prior to diagnosis. They were then asked to recall the impact on sexuality during

treatment, and to go on to describe how they have felt about their sexuality since their initial treatment (surgery, chemotherapy, radiotherapy) has ended. Two participants largely guided themselves through their story, the others required more prompts. At the end, participants were given details of the BACP Find a Therapist service, should they wish to explore any of the issues raised further. Following transcription, participants were emailed a copy of their interview to read and amend as appropriate. One participant requested very minor amendments, the remainder approved the initial transcripts.

### **3.4 Data Analysis**

Interpretative Phenomenological Analysis (IPA) was chosen to analyse the data. Smith et al. (2009) suggest that when people are experiencing something major in their lives, that they begin to reflect on the significance of what is happening; IPA aims to engage with this reflection process. “It is always concerned with the detailed examination of lived experience” (p.47). This resonated with the study’s aim and its philosophical underpinnings. Smith et al. (2009) see it as having strong links with various types of narrative analysis; IPA is centrally concerned with meaning-making and the construction of narrative is a way of meaning-making. Its idiographic focus is appropriate too, analysing each case individually, with the option to then compare themes across participants.

Taking the first interview, I listened twice, making initial descriptive notes in the right hand margin of the transcript. I adopted Smith et al.’s (2009) suggestion of considering the text from descriptive, linguistic and conceptual angles, using coloured pens to delineate between them, reading the transcript closely a number of times. Next, I noted emergent themes in the left hand margin (Appendix 7). I made a diagrammatic representation of these, and how they might relate to one another, with

a tentative division into superordinate themes and sub-themes (Appendix 8). I repeated the process with the remaining participants. Next, I laid the four sheets alongside one another and looked for commonalities, in order to begin to form themes across the cases. This was difficult; I was very aware of not wanting to dismantle the participant as an individual and make them one homogenous whole. It was reassuring to read that it is common to feel like this at first, and that the data would come back into a new kind of whole at the end of the analysis process; the IPA process is iterative as the researcher moves around the 'hermeneutic circle' (Smith et al. 2009). I utilised my reflexive journal extensively during the process to capture my thoughts and feelings, to heighten awareness of how my experiences and feelings were informing it (Etherington 2004). Listening to the interviews I noticed how particular experiences resonated strongly with mine, and how others surprised me as they were so different from mine. Self-awareness was crucial in this process to ensure I did not focus just on the parts that reflected my experiences and that I allowed the unexpected to take equal prominence. I created a master table of themes and associated quotes (Appendix 9). Next, I made difficult choices as to what to include; a word limit and the sacrifice of depth if I were to try to cover too much made this a necessity. So, I returned to my research question and asked what felt most important. I decided to focus on capturing something of the sense of changes over time, to reflect the re-writing of narratives, and also to examine in closer detail the impact of diagnosis on forming sexual relationships, as this area has been largely neglected by research to date.



### **3.5 Ethics**

Ethical issues must be considered carefully at all stages of a research study (McLeod 2003). The Chester University Research Governance Handbook (2013) and the BACP Ethical Framework (2013) formed the basis for informing and guiding the ethical considerations for my study, together with the BACP Ethical Guidelines for Researching Counselling and Psychotherapy (Bond 2004). McLeod (2011) highlights the distinction between 'procedural' ethics which include ethics committees, and written information for participants, and 'micro-ethics', which take place during the course of interaction with participants; with the need for moment by moment ethical decisions to be made.

As part of my submission for approval by the University Ethics Committee, and the BCC Service User Review Panel, a comprehensive Participant Information Sheet for potential participants was compiled, and clear consent forms based on standard departmental templates. (Appendices 4&5). Avoidance of harm is a key starting point for any study (Smith et al. 2009), this is reflected in the principle of beneficence (BACP 2013). I was mindful of the extremely sensitive, and potentially distressing nature of the topics I hoped to explore; I wanted participants to be clear in advance about the areas the interview would cover, confidentiality and the use of pseudonyms, and the process following the interview, in terms of how data would be used and stored. Signposting to post-interview support was important too.

The notion of informed consent is a cornerstone of participant research (McLeod 2003). Participants were encouraged to contact me prior to the interview if they had any questions, and during our interaction, I was certainly aware of moment by moment assessment of the participant's state of being, and the appropriate level of questions and prompts. I made it clear at the start of each interview that participants

were free to take a break at any time, and that they should only talk about areas they were comfortable with. King and Horrocks (2010) point out that interviews seek to elicit rich and detailed information, and that emotions are an integral part of this, counselling against terminating an interview due to emotional distress; in their experience it has been more useful for the participant to complete the interview. To me, it seems a delicate balancing act; in the event it was not an issue. The opportunity for participants to read the transcript and request that parts be omitted felt particularly important, in light of the candid and open responses participants had provided.

It was also crucial that I was aware of my potential vulnerabilities in relation to this topic. Bond (2004) notes the importance of the researcher's responsibility to self. I kept a reflexive journal, which I used to reflect on my experiences in relation to the research, and also had personal counselling, and supervision in place to discuss safely any material that surfaced in relation to my research.

### **3.6 Validity and Trustworthiness**

It has been challenging for qualitative researchers to establish criteria by which the validity of a study can be judged, as unlike quantitative research, qualitative studies do not seek to measure an objective reality, and include the active personal engagement of the researcher (McLeod 2011). He provides a set of practical guidelines to enhance validity, which I used to guide my research, together with earlier criteria from Elliot et al. (1999), and he suggests that the plausibility and trustworthiness of the researcher are the key issues. I sought to embody this by a variety of means. I have provided a clear audit trail of my research process, (Maykut & Morehouse 1994), from its inception to its conclusion, and have provided examples demonstrating how I analysed the data. I used member checks (Lincoln & Guba

1985) to ensure that participants felt the interview transcript was accurate, and reflected what they wished to say. I have mapped a context within which my study can be located (McLeod 2003), and I have also provided some biographical information for each respondent to situate them. I have been transparent, both with participants and readers, as to my position in this study as a member of the group I am researching. This openness and willingness to acknowledge my own experiences perhaps encouraged a more open, and so more valid response from my participants (Oakley 1981). The extensive use of verbatim transcripts in Chapter 4, hopefully enables participants' voices to be heard, in a 'valid' way, uncoloured by interpretation.

My use of a reflexive journal throughout the process, was also a major contribution to the validity of my research; ensuring that I continually monitored my role, by noticing anything arising from my frame of reference, this went some way to reducing "impositions of meaning" (Willig 2008, p16).

## 4. RESEARCH FINDINGS

*'May these words serve as encouragement.....  
to speak and to act out of our experiences....  
for silence has never brought us anything of worth.'*  
(Lorde 1980)

### 4.1 Introduction

Each participant presented a unique and complex picture of the impact of breast cancer on their sexuality; a flavour of their experience is presented here.

Something of the sense of changes over time are captured in the Superordinate Themes **Who am I now?** and **The Continuing Journey**, and the impact of diagnosis on forming new sexual relationships is examined in the Superordinate Theme **Who will want me now?**

The emergent themes are presented in Table 2:

**Table 2: Emergent Themes**

| <b>Who am I now?</b>        | <b>Who will want me now?</b> | <b>The continuing journey</b> |
|-----------------------------|------------------------------|-------------------------------|
| Not me anymore              | No-one will want me          | Ongoing losses                |
| Taking control              | Physical barriers            | Fertility                     |
| Living with my changed body | Broaching the subject        |                               |
|                             | Being accepted               |                               |

For context, it should be noted that none of the participants reported a sense of feeling uncomfortable with their sexuality before diagnosis. For example, Lizzie describes it as *pretty uncomplicated* (3/59).

Jessica, whilst comfortable with her body describes having *maybe still a few issues about being gay* (4/45), as she was in her first gay relationship.

## **4.2 Superordinate Theme: Who am I now?**

### **4.2.1 Sub-Theme: Not me anymore**

Three of the participants spoke of identity change or loss during their treatment. Jessica uses an arresting image in relation to surgery changing her identity. This is particularly striking, as the language of her narrative is generally quite unemotional:

*On the day it happened it's almost like you're going to death row or something, obviously you are going to wake up not the same* (15/245).

For Sadie, her altered body image during the treatment phase caused great distress. As she anticipates chemotherapy-induced hair loss:

*I'm going to look like some freaky kind of alien* (8/166).

It strikes at her very core, causing her to question her identity:

*...that (hair loss) is what defines you as a female, and to have some of that then taken away, are you then female?*(9/174).

Sadie makes many references to celebrity culture and what a woman is expected to look like; this seems important to her.

Lizzie also experiences a sense of disconnection from herself as she loses her hair and puts on weight:

*I do remember a sort of very distinct shift in feeling within me,... of kind of just losing my identity..., 'cos you sort of just don't look like yourself anymore, and you look in the mirror and that person doesn't look like you* (8/148).

She describes her changed appearance as losing a part of her 'toolkit' that she had relied on in social situations:

*...that just wasn't even in the game...and so it was like I'd stepped into someone else's shoes. I didn't feel sexy anymore, I didn't feel like myself anymore...(8/163).*

For both Sadie and Lizzie, hair loss is in some respects harder to cope with than the mastectomy, as it is visible to others. Lizzie, speaking of her double mastectomy illustrates this:

*...at the time, it was almost less challenging than losing my hair, 'cos you could cover it up and you didn't have to be constantly conscious of it (10/200).*

#### **4.2.2 Sub-Theme: Taking Control**

For Jessica, (who did not experience chemotherapy), research into reconstruction options is important in gaining some sense of control of how she will look post-surgery:

*I was probably quite obsessed with seeing what they looked like, and I had two people come to the office to see me, so I could have a look and feel (18/294).*

The oddness of this time for her is encapsulated here:

*...upstairs, feeling someone's breast in my boss's loo, but nothing sexual! (18/300).*

For Sadie, taking control of the outward signs of her diagnosis is important. There is almost a defiance as she speaks of how she transforms herself from cancer patient into glamorous woman:

*...right, put on the make-up, put on the wig, dress up, put on the killer heels, matching handbag, and go and rock that hospital room out (20/423).*

She has specialist hair work done. This marks the start of her return to womanhood:

*...it just made so much difference to...see myself in the mirror when I first got out of bed, or when I was in the bathroom, to have hair back, because then that was sort of stage one of coming back to being a woman again...(23/481).*

Lizzie whose identity is also bound up in her hair loss, similarly takes control:

*I went to that 18 month mark, and thought sod it, I'm just going to dye it blonde, and I dyed it blonde, and immediately it was like a shift, and...and I had it cut...into a bit more of a funky style...and then that summer, I think that was the start of when I just started to feel sort of like myself again, (11/225).*

There is a sense that Ceri blocks out any difficult feelings and takes comfort in the light-hearted directness of her nieces and nephews:

*...initially it was like all a shock, but I just got on with it, and I didn't think about it;...I sort of blanked it off. And having my nephews,...he did draw a picture of me with my bandana on,... and it had like a big bow on the back and he said, oh, that's auntie Ceri that is... I think having nieces and nephews around, that helped (15/291).*

#### **4.2.3 Sub-Theme: Living with my changed body**

Jessica describes how after her initial surgery she feels less happy with her body:

*When I had no nipple on one side, and 'cos I had an expander implant at first,...I was really asymmetrical, so undressed I felt kind of...didn't like my body as much anymore.(4/62).*

After further operations her body image improves:

*So I guess after I sorted out my symmetry and stuff and had a nipple tattooing I feel much better about myself (5/73).*

She expresses an acceptance that this will never feel the same as a 'real' breast, but there is a sense of the research she did paying off:

*...I'm very glad I went with the option I did go with, I'm kind of happy with it. I mean you know, there's certain things...I feel lumpy down one side, things like that, but obviously it's never going to feel like a real boob (21/352).*

Sadie speaks movingly of the struggles of looking at her mastectomy scar:

*But I would probably say it took me about a month to 6 weeks, before I could actually look at myself in the mirror, at my surgery scar (12/243).*

Offering an explanation for this:

*I was so worried I think that I'd just look down and I would just break down...I think part of it was, I've got to be strong (13/261).*

For Sadie too, once her surgery is complete her body image improves: *But then when I had the operation to sort of create the nipple, and then the tattoo,...I don't go out flashing myself, but...I am more than happy to wear a bikini (29/606).*

There is a sense of pride in coming through the experience:

*I'd say, probably if anything, I'm more likely to be strutting myself in my bra and knickers or my bikini. Because, in a way, I'm kind of wanting people to think, what's happened to her, oh my God, she's had breast cancer but hey look (49/1023), and in having the scars to prove it: because, yes I've got scars, but those scars are because I'm still alive, and I'm still here to tell the tale...(34/712).*

For Lizzie, there seems to be an ambivalence. Struggling to find the right words, she speaks powerfully:



*...still sometimes I guess, if I actually bother to look at myself in the mirror, sometimes I....sort of shock myself. You know, obviously I see it all the time, and I'm not really bothered by it, but sometimes when you really actually look at yourself, I sort of have moments of...sort of horror, you know,...cos it's sort of a mutilation isn't it, it's sort of a bizarre, and you know you've lost a part of your body and, (pause), that's sort of an odd thing, and most of the time I just don't really think about it, but occasionally, I...sort of remember, (29/586).*

There is a sense of disembodiment and disconnection for Lizzie following surgery; her implants feel separate from her:

*...they just don't really feel part of me, you know...it's like I've just got two things stuck on my chest...and even if I run my own hands over my body, they're sort of these, they're these foreign objects, (35/728).*

She considers having them removed, and this being kinder to her body which would then be 'all her' once more:

*...if I just got rid of them would it give my body just a chance to just heal, and maybe it would take a long time, but it would have a shot at just healing in a new way, and then it would all be me again (37/758).*

She notices how her feelings have changed over the intervening years; this is an ongoing process. She continues to reflect on how it might feel to have them removed:

*...me becoming more comfortable with myself, and my body, and being able to handle it I guess and being able to still feel like me, and not have them, whereas if I'd done it when I was 23, I don't think I could have handled it (34/711).*

Ceri speaks a lot about covering up her body since her surgery, and her words suggest it is not just her outward appearance that has changed:

*...I'd be showing...not showing yourself off, but, you know, wearing more revealing tops, so I was quite a bubbly and outgoing thing. But since the op now...I won't wear any dresses (5/94).*

She goes on to explain:

*So no, I'm just wearing all these things to...keep my arms covered. 'Cos you feel that you can, still can, see the scar, and the indentation where the lymph nodes were taken out (6/108).*

She describes the asymmetry of her breasts following her lumpectomy:

*I suppose it's because I'm quite big, so the one side is quite big, and the other side is like half the size. So obviously...they don't offer reconstruction when it's a lumpectomy (12/237).*

There is a sadness and confusion in her voice as she goes on to wonder why she was left like this.

#### **4.3 Superordinate Theme: Who will want me now?**

##### **4.3.1 Sub-Theme: No-one will want me**

Following the end of her relationship during treatment, Jessica expresses fears about dating again:

*I think I was really worried that no-one else would want me. (8/126).*

Although she has had a sexual relationship since her treatment, Sadie still has concerns about not looking 'normal':

*....'cos you're thinking, what if they see me undressed, and whilst I'm happy with the way I look, they think, you don't quite look like what a normal woman should look like,*

*whatever the definition of a normal woman is, and just run to the hills screaming...because that's what you sort of build up in your mind (30/635).*

She wonders too whether other factors will also put men off:

*...would he rather do that (go out with someone else) than go out with me, because I've had cancer, and perhaps because his dad had died of cancer (33/695), and...a guy might think, no actually I want to have my own kid, and actually I can't help in that department (44/927).*

For Lizzie, although she has sexual relationships during treatment, she feels unable to be proactive about this:

*...I didn't feel like I could go out and sort of look for a guy, because I just didn't feel sexy (13/268).*

She is also worried about the response she might get:

*...there's always that worry that they're gonna be completely unable to deal with it (15/310).*

Ceri writes off her chances of ever having a relationship:

*I just thought, that...I'd never be in a relationship ever again. Because obviously it was the low self-esteem, low self-confidence...and because of the treatment, you were so like up and down all the time, and the coping with all the side-effects is so draining isn't it, mentally draining, and I think it just really knocked my confidence quite a bit (16/304).*

#### **4.3.2 Sub-Theme: Physical barriers**

Jessica and Sadie have not experienced physical changes that interfere with sex:

*...I don't think it's particularly affected my sex drive really (Jessica 12/187).*

*...I think, so far, everything in that department seems to be absolutely fine (Sadie 45/946).*

Lizzie speaks of the shock of discovering some unwelcome side-effects of treatment, and there is a sense of being kicked when she is already down:

*...I hadn't really clocked all of that, and all of the ways that it interferes with the plumbing, was pretty challenging, and a bit of a shock, and not very nice. And again, to sort of be confronted with that, you know, when you're already feeling pretty vulnerable, with no hair, and with a guy you haven't seen for a long time (14/291).*

Ceri speaks poignantly and hesitantly of feeling inadequate as she embarks on a new relationship, and of the confusion of her altered sexual response:

*I just didn't feel as if I was fulfil...you know, fulfil,...fulfil(ling) his needs...But it could have been because sometimes it was quite painful, even with the lubricants. And then I think, just because it put you off as well, and sometimes you just, you felt you were in the moment, it was just like a light switch sometimes, it was weird, bizarre isn't it (8/143).*

#### **4.3.3 Sub-Theme: Broaching the subject**

Jessica, Sadie and Lizzie have all experienced disclosure to new sexual partners; when to mention it was explored by them.

There is a sense of the awkwardness of broaching the subject:

*probably when I got drunk with them (Jessica 9/145).*

Sadie reflects on the feeling of 'a rock and a hard place' concerning when to disclose, but highlights her sense of owning the information and it being a case of her choosing when to share:

*If you are then completely meeting someone anew, do you tell them on first date; it's probably not the conversation for a first date, but then when do you, you don't want to go so far down the line that actually you think somebody might think, well, you've hidden that from me. You think, well actually... but it's my, truth to hide,...and it's up to me to tell. (36/755).*

Lizzie adopts a kind of phased approach to disclosure, seeming to almost expect that some men may want to walk away:

*...Mostly I probably tried to make them aware of the fact that I had had some sort of operation, pretty early on, before we even kind of got to that stage. I suppose I wanted to give them the opportunity to check out nice and early, and then you know, as things sort of got a bit closer to something actually happening, I probably would be pretty explicit, again probably wanting to give them, either to just give them a bit of warning...walk away if they wanted to (16/316).*

For Lizzie, who had met several men since diagnosis, there is a sense of each new relationship bringing breast cancer back to the fore:

*...with another one, you have to tell them all about it all again, and worry about it all again, and it's a new thing, and it's sort of on your mind. (27/554).*

#### 4.3.4 Sub-Theme: Being Accepted

In contrast to their fears and expectations all participants have experienced acceptance:

For Jessica this is hugely reassuring, following her experience with her partner at diagnosis:

*...the two girls I had a bit of a fling with before I met my current girlfriend both were very accepting of it, they said it didn't matter to them, they didn't care... so that was kind of a positive outcome...because I guess maybe my ex-girlfriend, although...she wasn't horrible about it or anything, because she wasn't an overly sexual person,...she didn't want to touch my scar or anything like that (8/129).*

In this description of her current partner's reaction, her response goes beyond acceptance and feels something more like celebration:

*...she's always been very complimentary about it, how, you know, it's beautiful because it you know, it saved me almost, because if I hadn't had it done would I be here still? (11/172).*

Sadie meets a younger man who reacts positively to her reconstruction. In her comment below she seems to be almost making excuses for why this is the case:

*...I think he probably thought I was going to say, actually, I was a man (laughter). And I think to be honest, because it wasn't that, he was like, it's not a problem, and he had no issue with it whatsoever. But...24 year old guys, let's face it, as long as they're getting sex, that's all they want. (31/647).*

She sounds surprised: ....he didn't wince or anything, he didn't have a problem. He was actually very flattering, and you know, positive about the way I looked...so it was like actually, he's not run for the hills (32/662).

Lizzie too expects things to be different:

...despite not having a nipple on one side, I've been probably with quite a few different guys since I was treated, and not a single one of them has been remotely fazed, not even a little bit weirded out, which I think is pretty amazing really (16/330).

There is a bitter-sweetness to having a long-term partner; some difficult feelings did not surface until then:

...it's sort of brought up things which are difficult again, because...I wish I could have been with him when I still had my breasts for instance (28/564),...it's just a real sort of shame, I suppose, and so sometimes I sort of find that a bit difficult, in a way that I didn't really find difficult when I was with guys that I didn't really care about (28/573).

Ceri expresses gratitude for the patience of her new partner:

because of the way he was,...you just felt that you were comfortable...because he didn't rush, or he wasn't pressured, I think he was a blessing, you know what I mean? (5/86).

Like Sadie, she also attributes his acceptance possibly to factors other than herself:

But he's a little bit older, than myself, so whether or not, it might have been different if it was...(11/205).

## 4.4 Superordinate Theme: The Continuing Journey

### 4.4.1 Sub-Theme: Ongoing Losses

Participants articulated a sense of the ongoing nature of their losses from breast cancer to varying degrees. Lizzie in particular spoke at some length. As she herself alludes to, perhaps the fact that she was diagnosed so young has contributed to some 'delayed losses:'

*...there's all this other stuff that I hadn't really clocked, and I'd say the last few years for me have almost been more emotionally difficult, than when I went through the treatment, because there's been so much other stuff which at the time, I just completely put in a box because there was so much going on, at such a young age, I couldn't, and also just stuff that wasn't important to me then (23/473).*

For example speaking about the impact of her decision to have a double mastectomy, and how this has hit her much later on:

*...although obviously I knew that I wouldn't be able to breastfeed, and that was in a way sad, as I say, that child fertility thing was so far down my list of priorities behind surviving...not really understanding, 'cos how could I at 23, never thinking about children, just what a big deal it is, and now I get it (22/443).*

She speaks poignantly about missing her breasts, articulating a deep sense of loss:

*I often will have a sexual experience, and feel actively quite sad, and not be able to enjoy it, because I get kind of caught up in that feeling of, feeling really sad about what had to happen, and so that continues to be an issue for me (46/952).*

Ceri struggles to understand why she still has no sex drive, and feels there is something wrong with her:



*...I could quite easily go without any...sexual relationship, it's just not there at all, it's weird isn't it...you think there's something wrong with you, well there is...and like the switch, you'd think the switch would have come back on now, wouldn't you after all this time, nothing, weird isn't it (14/265).*

To combat menopausal hot flushes she changes her wardrobe and this can add to a sense of unattractiveness:

*...everything's got to be 100% cotton and some of those clothes aren't particularly attractive (18/339).*

For her, the ups and downs of the breast cancer journey continue:

*...people seem to think once you've had it that's that, but it's like at the back of your mind, and although you get on with life and everything, you still have, you feel like you're on a rollercoaster...of emotions (24/453).*

#### **4.4.2 Sub-Theme: Fertility**

For Jessica and Lizzie infertility is a possibility. Jessica expresses early concerns that she will be 'left behind', but this seems to be less likely now:

*I suppose at the time you kind of think all my friends will have had children and I won't have...and actually you know I'm two years into Tamoxifen now, so it's only another 3 years, and quite a few of my close friends haven't got kids yet...(33/571).*

Lizzie considers her options, and reflects that although fertility is a concern, other losses have possibly felt more significant.:

*...my overall stance that you know, if I can't have children it won't be the end of the world, that still is true, so you know, I am very open to adoption and I'm also very open to just not having children, if that is the path that we go down.. some people just*

*can't have children anyway, quite aside from anything, so I'm pretty open-minded about the whole thing in that way, but I think it's probably the double mastectomy and the breastfeeding that has kind of shook me up more I would say than the fertility (20/402).*

Certainly for Ceri, and probably for Sadie, loss of fertility is a reality.

Sadie recalls her weighing up of options at the time:

*Just, what's the point of having your eggs frozen, if you delay your treatment and it makes it worse, and then you're dead, and you still can't use them anyway(40/845).*

She describes an upsetting incident at work where everyone seems to be having babies, and reflects on changes since then. There is a sense of her re-writing her narrative in relation to children:

*...it was 2 years down the line; it was probably still very raw, whereas now it's probably, it's sunk in and, you know, I'll be the cool auntie to everyone else's kids...who's the bad influence, and causes the parents problems (44/920).*

She rationalises, acknowledging that it is hard for her:

*...with everything that happens in life, you have to compromise, so if my compromise for still being here, is the fact that I might not be able to have children naturally, you know, it's a tough thing to deal with, and it has got me upset, and you know, I cannot watch One Born Every Minute (45/955).*

For Ceri, there is a sense of sadness at being overlooked as a single woman; she was not offered any options to preserve her fertility:

*...at the point of diagnosis they asked if I was in a relationship, and I'd said not at that time, and then they just said because it was Grade 3, we need to get on with it (9/162).*

She works with children and although she now feels able to continue, her last comment hints at continuing sadness:

*I thought about, wondered about giving up that job, but obviously I've managed to get through that and just, you know, but sometimes it does pull at you a little (10/189).*

## **5. DISCUSSION**

### **5.1 Introduction**

This study sought to explore the impact of breast cancer on the sexuality of young, single women.

Discourse around cancer may give the impression that once treatment is over, a patient no longer thinks about their illness, but emotional descriptions of memories of treatment show that this is far from the case (Thomas-Mclean 2004). It was a striking feature of my interviews, how vividly participants recalled particular points in their treatment; Jessica's "death-row" analogy (see section 4.2.1) was just one example of this.

Schover (1994) suggests that sexual life pre-diagnosis is a stronger predictor of sexuality issues than breast surgery. My findings would seem to indicate that a positive sexual self-image prior to diagnosis does not protect women from the impact of breast cancer on this area of their life. One can of course speculate that a poor adjustment prior to diagnosis would result in a more severe impact.

The following discussion addresses each Superordinate theme in turn, linking my findings to literature as appropriate.

### **5.2 Who am I now?**

Two participants, Sadie and Lizzie presented striking descriptions of the profound changes to their sense of identity during treatment. Jessica did not undergo chemotherapy so was not affected by hair loss; the sense of change from losing a breast was powerfully evoked in her comment likening the mastectomy surgery to "*going to death row*" (15/245).

The profound impact of chemotherapy-induced hair loss on identity emerged in Sadie and Lizzie's stories. This aspect of breast cancer is neglected in terms of studies that focus on it (Power & Cordon 2008). Citing a study by Freedman (1994), that was not specifically about hair loss, Power and Cordon report that almost half of participants felt their hair loss to be more significant than loss of their breast. This may seem a surprising finding, but the participants in this study echo this, and speak of the fact that a missing breast can be covered up by clothes, but that having no hair is more visible. This supports views expressed in earlier research (Wilmoth 2001; Thomas-Maclean 2004; Hefferon 2008). The links with female identity are made clear; Sadie questions whether she can even identify as female without hair, and her use of the word "*alien*" illustrates her sense of disconnection as she looks in the mirror. This happens for Lizzie too, who speaks of feeling like she had "*stepped into someone else's shoes*" (8/163), and links her hair to feeling sexy. The pervasive cultural images of beauty incorporating hair are mentioned by both, and the impact of those images is clear. Perhaps too, there is something especially traumatic in experiencing hair loss alongside breast loss; a double assault on feminine identity.

There appears to be resonance with Wilmoth's (2001) finding that women who take control by finding out as much information as they can about treatment and side-effects, often adjust well, coming through breast cancer with their self largely intact. Jessica spoke extensively about the research she did, and of subsequently being satisfied with the reconstruction option she chose. Sadie and Lizzie took steps to take control of their hair loss and re-growth and articulated the positive effect of this. Whilst it is unwise to make direct comparisons, there was less of a sense of agency throughout Ceri's narrative, and a lack of choices given to her, the impact of which she appears to continue to struggle with. Much of Sadie's narrative concerns her efforts during treatment in terms of outward appearance; hair, make-up, clothes, and

this resonates with Broyard's (1992) statements about the importance of adopting a 'style' during illness in order to combat the sense of his sense of self shrinking. There was a sense that Sadie had taken care of how she looked prior to her illness; this may fit with the idea that those who consider body image to be an important part of their attractiveness and self-worth, struggle more to adjust to treatment (Kissane et al. 2004). The impact on this group will arguably be greater as appearance is more important to them in terms of identity.

There is a real diversity of experiences amongst the participants as they adjust to their altered bodies. The importance of a nipple in defining a breast comes across; for Jessica and Sadie once this part of their surgery is complete they feel happier with their appearance. Sadie goes so far as to articulate a sense of pride about her scars and what they signify. For Lizzie, who has not had a nipple reconstruction as she does not wish to subject herself to more medical procedures, she still speaks of occasionally viewing her new body in terms of "*horror*" and "*mutilation*." This sense of the effects of surgery remaining, in spite of a degree of adjustment, echoes the findings of Larder (2010). Lizzie also describes how her implants feel like "*foreign objects*" (35/726), and expresses how her feelings concerning the necessity of them have changed, as she has become more comfortable with herself over the years since diagnosis. Adams et al. (2011), describe women engaging in a normalising process, as they adjust to their altered body, and it seems that Lizzie's definition of what she can accept has shifted with time, and she believes now that she would "*still be able to feel like me*" (34/712) without her implants. This suggests normalisation to be an ongoing and fluid process, as definitions shift for people over time.

It is interesting to note that it is Ceri, who had breast-conserving surgery (lumpectomy) who continues to have concerns in terms of covering up her body, both

in public and with her partner. Intuitively it might be expected that this would have less impact; it is only upon hearing Ceri's story that we find out why it is so difficult for her. As she did not have a mastectomy, she was not offered any reconstruction and has been left with breasts of greatly differing sizes; making her self-conscious even when dressed, and resulting in her completely changing her style of clothes, and it seems she also mourns a deeper impact on her identity as she describes how she used to be "*quite a bubbly and outgoing thing*". (5/96). In terms of research, the findings fit with Emilee et al.'s (2010) review, which suggests mixed results as to the impact of type of surgery on sexuality. It seems that it is only by hearing individuals' stories that the truth for them can be revealed, and that generalisations are unwise and unhelpful.

### **5.3 Who will want me now?**

The anxieties of the participants as they contemplate dating post-treatment, echo the findings of earlier studies (Glushoski et al. 1998; Holmberg et al. 2001; Kissane et al. 2004). Apprehension was expressed by all of the participants at the possibility of ever finding an accepting partner; in Glushoski et al.'s research this resulted from a mixture of women feeling they had become more selective after their illness, and of feeling men would think they were less appealing. There were many comments from this study's participants about feeling unattractive and not conforming to the normal image of womanhood. This fits with existing research (e.g. Archibald et al. 2006).

Lizzie and Ceri had both experienced physical issues with intimacy, and for Ceri this remained ongoing. The shock for Lizzie of the changes she experienced during treatment, and for Ceri the bewilderment that accompanied her altered sexual response, possibly reflect the lack of information proactively given to young women about this. This is in line with the comments of Gould et al.'s (2006) participants that

they could not find answers to their questions about the effect of treatment on their bodies and how to relate to themselves sexually again. Their experiences illustrate some of the symptoms identified by Howard-Anderson et al. (2012) including lack of libido and vaginal dryness. The quotes from Ceri and Lizzie bring this to life and indicate the emotional impact of these unexpected physical changes.

Disclosure of diagnosis to a potential new partner can be a 'chilling prospect' (Holmberg et al. 2001). This may sound dramatic, but for the three participants who have done this, there was certainly great apprehension. Jessica, using the humour characteristic throughout her narrative, hinted at this as she described how alcohol facilitated disclosure. Lizzie tended to give hints early on in the process. Sadie's reflections on the uncertainty of when to disclose appear to be common; there are similar quotes in earlier studies (eg Corney et al. 2014; Gluhoski et al. 1998).

Not much in the literature details how women went about disclosing, and the results of this; the findings hopefully add a little to the picture. A notable exception is Whitney's (1988) detailed thesis, which illustrates the uniqueness of each woman's experience. Overall, Whitney's participants present a mixed picture in terms of positive experiences of dating post-cancer, with some very encouraging stories and some less so. One of Whitney's participants expressed anger at having to explain her diagnosis again each time she met a new partner; Lizzie mentioned having to do this, but rather than anger; there was a frustration at breast cancer coming back to the fore over and over again.

The experiences of the participants present a more universally optimistic and encouraging message about the realities of dating post breast cancer, than other studies. Lizzie and Jessica had both met and dated several people before embarking on their current long-term relationships. Sadie had several dates with a man, and



Ceri was in a relationship with someone who had been a friend during her treatment. Without exception, each of these experiences had been good, in terms of partner's acceptance. In contrast, one of the participants in Corney et al.'s (2014) study reported that an ex-boyfriend warned her not to tell men about her diagnosis as they would not want to date someone who might get ill again. This warning was then borne out by her experiences; as the men she dated and disclosed to disappeared. Some of Gluhoski et al.'s (1998) participants also described rejection due to fear of recurrence, but this was not mentioned by the participants in this study as an issue, apart from one comment from Sadie who wondered about one potential partner, who had been a friend many years ago, and whether his choice not to date her was related to her diagnosis, perhaps because his dad had recently died of cancer. She also wondered whether her loss of fertility may be a deterrent; this is also mentioned by Corney et al. (2014) as a fear amongst her participants.

For Jessica, there is a sense of a real contrast between the reaction of her partner at the time of diagnosis, and the response of her new girlfriend who celebrates her reconstruction and her scars because this is what has saved her life. This chimes with Wilmoth's (2001) model that includes 'influencing pieces' – factors that have an impact on how a woman moves through the process of having cancer. One of these is the supportiveness of partners, and she quotes a participant speaking of their partner telling them how beautiful they still are. Jessica speaks a lot throughout her narrative of the impact of others' responses on her. In line with their expectations, Sadie and Lizzie express some surprise and disbelief that they are accepted by partners. This again highlights how expectations of what is culturally acceptable are entrenched within a woman's sense of identity. It was interesting to hear both Sadie and Ceri speculate as to the reasons why their post-treatment body is accepted by men; for Sadie it was about young men just wanting sex, and for Ceri the fact that her

partner was older. It seems it is hard to believe that their partners just accept them for who they are regardless of how they look.

There is not much qualitative research that considers the longer-term impact on relationships. One of Whitney's (1988) case studies had been diagnosed 5 years ago. Kissane et al. (2004) notes that research suggests, whilst most women adjust to their altered body, some will suffer long-term impact on sexuality; some studies two or three years post-diagnosis indicate this. Lizzie, diagnosed 6.5 years ago, spoke poignantly of the sadness she still feels that her long-term partner did not know her when she had breasts, and links this to the depth of feeling she has for him.

#### **5.4 The Continuing Journey**

Continuing exploration of the longer-term impact on sexuality, the third Superordinate theme resulted from participants' talking about the ongoing changes and losses arising from their diagnosis and treatment. Aside from a continuing apprehension around whether potential partners would accept her body as she does, menopausal hot flushes, and her not insignificant sadness at fertility loss, which will be discussed later on, Sadie presented as living life to the full and being open about what she had been through, and almost defiant. Jessica seemed to feel she had been fortunate not to have experienced chemotherapy and its side effects and seemed accepting of her new body, helped greatly by her partner's response to it. There was a sense of moving forward and it not being at the forefront of her mind on a daily basis anymore.

Lizzie had the most to say about the ongoing impact, and provides a rare insight into the experience of someone diagnosed in their early 20's. The 'off-time' nature of her diagnosis is extreme; she is 'out of sync' with her peers (Adams et al. 2011), so it is perhaps not surprising that her feelings and priorities have shifted over time. She illustrates the concept of 'balancing' (Adams et al. 2011) as she describes how

immediate concerns about survival, together with her life-stage pushed fertility and the importance of breast-feeding down the list of priorities. Her distress at loss of ability to breastfeed is echoed by a participant in Kirkman et al.'s (2014) study. She articulates with poignancy the ongoing grief at her loss of breasts speaking of often feeling *actively quite sad* during sex (46/952). This highlights the profound and enduring nature of the impact of surgery for some women: "Losing any part of the body in a mutilating operation, however necessary and however life-saving the surgery, involves grieving. This process is long and painful for some of us" (Kitzinger 1985 p.297). For Ceri, the "*rollercoaster*" (24/455) of emotions continues, and there is a hint of the huge sense of loss expressed by Klaeson et al.'s (2011) participants, as to the sadness at no longer feeling any sexual desire. Her language is quite matter of fact, but her tone is not.

Young, single women can have limited options for fertility treatment and face dilemmas around having children (Corney et al. 2014); the participants offered a range of experiences. The idea of 'balancing' (Adams et al. 2011) was evident in the reflections of some participants. For instance Sadie speaks of the futility of having her eggs frozen if it means that she later dies because her treatment was delayed to harvest them. Years later, she is still balancing the fact that she is unlikely to be able to have children against the fact that she is still alive. She re-writes her narrative (Neimeyer et al. 2002), reflecting on how the rawness she felt earlier on, this has now softened a little and she re-imagines her future as "*the cool auntie*" (44/921). She invents a 'consoling plot' (Kermode 1967, cited in Kirkman et al. 2014) to make life meaningful. This is not to underestimate the continuing sadness she clearly feels.

Ceri's story echoes the experiences of some of Corney et al.'s (2014) participants, in that as a single woman she was not offered any options for preserving her fertility,

and she speaks of wishing there had been information readily available at the time. Like Sadie, it seems an adjustment process has taken place, to the extent that she has been able to continue in her job with children; she felt she may not be able to. But her continuing sense of loss is evident in her words, there is something of a 'preoccupying sorrow' (Kirkman et al. 2014).

Viewing each participant's story in terms of illness narratives (Frank 1995), elements of each type; restitution, chaos and quest are evident throughout. The restitution narrative, in which society demands a return to being 'good as new', is shown as flawed as the women progress through the confusion, and 'chaos' of diagnosis and treatment to the realisation that they will have to find a new 'normal' – there is no going back. Each story contains a sense of a quest narrative; all participants work with a breast cancer charity sharing their story with others. This quote from Frank (1995) seems pertinent: "Human illness, even when lived as a quest, always returns to mourning" (p.136).

Wilmoth's (2001) model of taking in, taking hold and taking on could be said to link with the idea of differing types of narratives, and like participants in this study, time did not appear to be a predictor of adjustment. The 'influencing pieces' of taking control of treatments and information, and the supportive relationships did appear to be important.

A report from BCC (2014) on body image, that was published during the writing of this dissertation provides further evidence of the range of impacts on sexuality. Whilst this is a policy report, and its main focus is on improvements to services and support, it contains a selection of often poignant quotes from women, which bring the topics to life, and reflect that for some treatment has resulted in ongoing difficulties and mourning of losses. Many of these reflect the mix of experiences of this study's

participants, and capture the disappointment expressed, particularly by Ceri about the lack of information to prepare and support them for what is ahead.

## **6. CONCLUSION**

### **6.1 Limitations**

There are some obvious limitations of this study. The sample size was small, and therefore did not represent a broad spread of demographic group and experience. All respondents were involved with BCC. The three volunteers are likely to have engaged with their own experiences previously, as part of their role. The fourth participant, had also been interviewed by BCC to tell her story. As such, it could be argued that they did not have the 'freshness' that others may have done, although it could also be said that volunteers may be more grounded in their experiences and may have reflected on them more, partly as a result of their work.

Inevitably, analysis was conducted through my lens, and, another researcher may have highlighted different aspects of participants' experiences from those I choose to focus on.

### **6.2 Outcomes**

This study did not seek to prove or disprove, but rather to add some threads to the colourful tapestry of women who have been generous enough to speak with researchers like myself and share something of their experience. Whilst there were certainly themes across participants that resonated with one another, and with existing research, the uniqueness of each woman's experience was striking, and is perhaps the most important outcome to note. A finding that differed from some earlier studies, was that of universal acceptance from prospective partners of participants' diagnosis. It is hoped that this may serve as encouragement to others.

By interviewing women who were several years post-diagnosis, I hoped to convey a sense of changes over time, and each experience was very different. Whilst, each

woman is moving forward in positive ways in their own lives and helping others by sharing their story, there is certainly a sense of lingering sadness and long-term impacts for some participants, and these findings add to the limited qualitative research on longer-term adjustment. They demonstrate, it is not a case of getting over the losses that breast cancer has brought, but of adapting to an altered life narrative.

### **6.3 Implications for Practice**

Many therapists are not well-informed about breast cancer and its treatment (Anllo 2000). In undertaking this study, it was my hope that the counselling community may gain some insights into the types of issues faced by younger, single women with breast cancer. Although the disease in younger women is relatively uncommon, counsellors may encounter members of this group during their career. Whilst each journey is unique, the themes of loss, identity change, and re-writing life's narrative to some degree, seem universal. Person-centred therapy, with its emphasis on the client as expert in exploring the areas they need to, in a supportive non-judgemental environment, seems an ideal setting for the process of making sense of the experience and exploring the challenges arising from it.

### **6.4 Future Research**

This study has only been able to give a flavour of the experiences of four women who have lived through the experience of breast cancer at a young age. Areas worthy of note and further elaboration include the impact of cultural images of womanhood on identity in breast cancer patients, explored in the narratives of two participants. A much fuller exploration of the re-writing of life narratives as a result of diagnosis would also be interesting. Body image during treatment yielded a much richer seam than I had anticipated, and could warrant a full study in itself; hair loss and its impact

on identity being a particular issue. Further research on the actual rather than anticipated experiences of single women once they begin dating may be useful; my study indicates that outcomes are more favourable than predicted, and it would be interesting to see if this is replicated elsewhere.

## **6.5 Reflexive Response**

As I set out on this research, there was a sense of adventure and a passion for my topic, mixed with some apprehension as to how it would feel for myself and my participants to relive very intimate, and often painful experiences.

As I met each woman, and heard her story, I felt privileged to be entrusted with it: *These words are like a precious gift in my hands. Like a potter, I need to take care to shape them into something that feels right – a great sense of responsibility* journal 16/8

Parts of interviews inevitably touched on my experiences, and at points I was transported back to my diagnosis; I tapped into my losses and found myself with tears in my eyes whilst transcribing a particularly poignant segment of a tape, as a participant described the last time she had sex with two breasts. I felt a particularly strong connection with one participant, and had to take a step back to ensure that I did not select quotes that reflected my experiences, to the detriment of presenting a more rounded picture. The discipline of writing in my reflexive journal throughout the project proved key in bringing to awareness how ‘my stuff’ was influencing my work. I caught myself feeling surprised at some aspects of participants’ experiences, and this again brought my involvement to the fore; perhaps I had expected everyone’s story to echo mine.



When I began analysis, I was very aware of wanting to include 'everything'; feeling passionately that it was all important, and that I wanted to do justice to my participants and their stories. Consequently, I was initially rather over-ambitious and created too many themes. One area that I found myself more passionately drawn to than anticipated was around cultural images of womanhood, and the impact of these on mastectomised women; sadly I could not fit this in. It did however inspire me to write a letter to the Guardian on this topic in response to an article on breasts, and I was pleased to get this published.

Undoubtedly this experience has impacted on my personal journey. As I come to the end of my writing, I find myself living through the dating process described by my participants; it has felt odd to be writing about something, whilst simultaneously testing it out for myself; almost as if I am participating in my own study. As I embark on a new relationship, my experience, as it has always been, is one of being accepted, seemingly without hesitation. I find myself feeling more confident and comfortable this time round. Doubtless, the strength of the relationship has been key in this, but maybe in part, this research was about me seeking out other single women and validating my feelings through hearing them describe theirs. In doing so, it has perhaps helped to shift something that had become stuck for me. In hearing others' stories I am changed (Frank 1995). I do not think of my participants as any less beautiful as a result of their surgery, and I am starting to feel more able to apply this to myself.

It has struck me that whilst I have made several 'breast cancer' friends, that none of them has been both young and single. Whilst I hear other women's stories in my support role as a BCC volunteer, this has been a very different process, and at the

end of it I feel less alone, and I hope that perhaps when they read this, my participants and others will too.

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## Electronic Literature Search Strategy

| Search Terms                              | Sources                      |
|---|------------------------------|
| breast cancer                             | <b>Libraries</b>             |
| breast cancer AND sexuality               | Chester University Library   |
| breast cancer AND sexuality OR body image | Liverpool University Library |
| breast cancer AND single                  | <b>Databases</b>             |
| breast cancer AND unmarried               | PsychINFO                    |
| breast cancer AND sexuality AND young     | BACP dissertation database   |
| breast cancer AND single AND sexuality    | Taylor Francis on-line       |
|   | PubMed                       |
|   | <b>Websites</b>              |
|   | Google Scholar               |
|   | Breast Cancer Care           |
|   | Cancer Research UK           |
|   | Google searches              |

## Recruitment Advertisement



### **Young, single and treated for breast cancer: making sense of my sexuality**

I am a postgraduate Counselling student at Chester University, and I am also a Breast Cancer Care volunteer.

I am carrying out a research project, exploring the impact of a breast cancer diagnosis on sexuality, in younger, single women.

Sexuality may include areas such as body image, dating and relationships, libido (sex drive), early menopause, fertility.

I am looking for:

- younger women (under 45 at diagnosis)
- at least 3 years post diagnosis
- who have been single at some point since their diagnosis

Taking part in the study will involve an hour long face-to-face interview to tell your story. I am based in Cheshire, so ideally am looking for participants in the North-West.

If you are interested in taking part, and would like to find out more, please contact me at:

@chester.ac.uk

Thank you

Sue Shortt

Research Advertisement – Version 2



**Can you help?**

- Are you a younger woman who has had a breast cancer diagnosis?
- Have you been single at some point since then?
- Would you be willing to talk about the impact of breast cancer on areas such as dating and relationships and body image?

**This is an under-researched topic, and as someone with personal experience of breast cancer, I would like to help the voices of this group to be heard, and increase understanding amongst health professionals who work in this area. This study is supported by Breast Cancer Care.**

**If you are interested in finding out more about taking part in my project, I'd love to hear from you - please email me at [\\_\\_\\_\\_\\_@gmail.com](#)**

**Thank you, Sue Shortt**

## Inclusion Checklist



University of  
Chester

## Young, single and treated for breast cancer: making sense of my sexuality

## Inclusion Checklist

Thank you for your interest in this study. Please complete the below and return to [\\_\\_\\_\\_\\_@gmail.com](mailto:_____@gmail.com)

Name \_\_\_\_\_

Age \_\_\_\_\_

Location \_\_\_\_\_

Telephone number(s) \_\_\_\_\_

Email address \_\_\_\_\_

Please delete as applicable:

**Breast Cancer Care Volunteer/Breast Cancer Care Service User**

Date of breast cancer diagnosis \_\_\_\_\_

Breast cancer treatments \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**Relationship status since diagnosis (please list in order if this has changed eg single, partnered, single)**

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

If you have any questions, please do not hesitate to contact me at the e-mail address above. Thank you

## Participant Information Sheet



University of  
Chester

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## Participant Information Sheet

### Research Title

Young, single and treated for breast cancer: making sense of my sexuality

### Background

I am a third year postgraduate student studying for an MA in Clinical Counselling at Chester University. My interest in this topic stems from the work I do with Breast Cancer Care as a Someone Like Me volunteer, in which I hear the stories of younger single women about the impact of breast cancer on their sexuality.

Although there has been a substantial amount of research in the general area of adjustment following a breast cancer diagnosis, there is little published research on the experiences of younger, single women and how they make sense of their sexuality following their treatment. I would like to enable their voices to be heard, and increase understanding amongst health professionals who may work with this group.

Breast Cancer Care has agreed to assist me in finding suitable participants.

### Invitation

I am inviting each participant to tell their story about the impact of their breast cancer diagnosis on how they feel about their sexuality.

Sexuality may include:

- Body image
- Dating and relationships
- Libido (sex drive)
- Early menopause
- Fertility

If you take part, I will invite you to consider the above topics in relation to how you felt before your diagnosis, during treatment,\* and particularly how you have experienced your sexuality since then. There may be other areas not on the list that are important to you and I would like to hear about those too.

\*initial treatment such as surgery, chemotherapy, radiotherapy

### **Am I eligible to take part?**

Participants should meet the following criteria:

- Diagnosed with breast cancer at least 3 years ago
- Female
- Under 45 years old at point of breast cancer diagnosis, and over 18 years old
- Single (defined as not in a partner relationship) at some point since their breast cancer diagnosis
- Breast Cancer Care Volunteer or Service User
- Fluent in English
- Feel ready and able to take part and share their story

### **What will happen?**

If after reading this information sheet you are interested in taking part, the next step is to complete and return the attached Inclusion Checklist. In the event that the study is over-subscribed, recruitment decisions will be made based on the biographical data provided, to ensure a mix of ages and circumstances.

I will then contact you to let you know whether you are eligible for the study. If so, I will telephone you to arrange a mutually convenient time and place to meet.

You will be asked to provide your written consent before the interview begins.

When we meet I will invite you to explore your experiences; this will take the form of a digitally recorded interview lasting no more than an hour. Any travel expenses will be reimbursed.

After the interview, I will transcribe the recording, and you will be offered the opportunity to check this for accuracy. Once my analysis is complete you will also be able to read the results if you wish.

**What are the potential advantages of taking part?**

You may value the opportunity to tell your story. By taking part, you will be contributing to increasing awareness of this under-researched topic.

**What are the potential disadvantages of taking part?**

There is a risk that talking about this sensitive topic may bring up painful feelings for you. I will ensure that you are aware of all avenues of support within Breast Cancer Care, and will also provide you with a list of BACP accredited counsellors in your local area, should you wish to explore the subject further.

**Participants' rights**

Your participation in the study is voluntary and you are free to withdraw at any point before data analysis has begun, without giving a reason and without detriment to yourself.

You will be offered the opportunity to read and agree the transcript of your interview, and at that point will be giving consent for the data to be used in the study.

Once final consent has been given and the analysis begins, you will not be able to withdraw or change the material, as the data will have added into the group data set, and it will no longer be possible to isolate it.

**Confidentiality**

The interview will take place in an environment where privacy can be ensured.

I will give you a pseudonym, which I will use throughout the research to protect your anonymity. Verbatim quotes may be used in the final dissertation but I will ensure that I only use material that will not identify participants.

The transcripts and related data will be securely stored for a period of five years, by me, and then destroyed. Upon satisfactory completion of my MA in Clinical Counselling the recording will be securely destroyed.



**What will happen to the results**

The results of the research will be part of my dissertation which will be submitted to Chester University. The dissertation will be available in the Department of Social Studies and Counselling and also may be available electronically.

The findings will also be shared with Breast Cancer Care and may also be included in subsequent papers put forward for publication.

**What if I am unhappy with the process?**

If you are unhappy with any aspect of the process, I would ask you to contact me, Sue Shortt, in the first instance: [@gmail.com](#) or [@chester.ac.uk](#)

If the outcome is not satisfactory, you can contact my Research Supervisor, Dr Peter Gubi

If the issue still cannot be resolved, please contact the Dean of Social Sciences, David Balsamo

**Any questions?**

Please feel free to contact me via email with any queries: [@gmail.com](#)

Thank you for your interest in this study.

## Consent Forms

University of  
Chester

M. A. in Clinical Counselling Research

University of Chester

## Consent Form: Audio/Digital Recording of Interview

**Title of Study: Young, single and treated for breast cancer: making sense of my sexuality**

I .....hereby give consent for the details of a written transcript based on an audio/digital recorded interview with me and..... to be used in preparation and as part of a research dissertation for the M.A. in Clinical Counselling at the University of Chester. I understand that my identity will remain anonymous and that all personally identifiable information will remain confidential and separate from the research data. I further understand that the transcript may be seen by Counselling Tutors and the External Examiner for the purpose of assessment and moderation. I also understand that all these individuals are bound by the British Association for Counselling and Psychotherapy Ethical Framework for Good Practice in Counselling and Psychotherapy.

I understand that I will have access to the transcribed material and would be able to delete or amend any part of it. I am aware that I can stop the interview at any time or ultimately withdraw the interview, without giving a reason or explanation, at any point before data analysis begins. Upon satisfactory completion of the M.A. in Clinical Counselling the recording will be securely destroyed. The transcripts and related data will be securely stored for a period of five years, by me, the researcher, and then destroyed.

Excerpts from the transcript will be included in the dissertation. A copy of the dissertation will be held in the Department of Social Studies and Counselling and may be made available electronically through Chester Rep, the University's online research repository.

I consent to some of the material being used for publication and/or presentations at conferences and seminars. Every effort will be made to ensure complete anonymity.

Finally I confirm I have read and understood the attached Information Sheet and was given the opportunity for further explanation by the researcher. I believe I have been given sufficient information about the nature of this research, including any possible risks, to give my informed consent to participate.

**Signed****[Participant]**.....**Name- Please Print**.....**Date** .....**Signed [Researcher]** .....**Name-Please Print**.....**Date**.....



University of  
Chester

# RESEARCH CONSENT FORM

Title of Study: Young, single and treated for breast cancer: making sense of my sexuality

Name of Researcher: Susan Shortt

Name of Participant:.....

If you are happy to participate please complete and sign the consent form below.

Please  
Initial  
Box

1. I confirm that I have read the attached information sheet on the above project and have had the opportunity to consider the information and ask questions and had these answered satisfactorily. ☐
2. I understand that my participation in the study is voluntary and that I am free to withdraw at any time before data analysis has begun, without giving a reason and without detriment to myself. ☐
3. I understand that after reading and agreeing the transcript of my interview, and giving my written consent, that my data can be used in the analysis, and my right to withdraw from the study will cease. ☐
4. I understand that the interviews will be audio recorded. ☐
5. I agree to the use of anonymous quotes. ☐
6. I agree that any data collected may be passed to other researchers. ☐

I agree to take part in the above project

|                               |       |           |
|-------------------------------|-------|-----------|
| .....                         | ..... | .....     |
| Name of participant           | Date  | Signature |
| .....                         | ..... | .....     |
| Name of Person taking Consent | Date  | Signature |

## Interview Guide

### Young, single and treated for breast cancer: making sense of my sexuality - Interview Guide

This discussion is really about you telling me your story. I might come in with prompts and questions from time to time but I'd like it to be fairly free flowing.

I'm interested in the impact of your breast cancer diagnosis on how you experience your sexuality; things like body image, dating and relationships and any areas that may have been affected by treatment, for example menopausal status, fertility and sex drive. There might also be other topics that are important to you.

I am aware this is a sensitive topic – please discuss things at a level you feel comfortable with.

We've got an hour together and I'd like you to consider before, during and after your treatment – we'll spend most of our time on the after.

Before we start I need to ask you to sign the consent forms – check have had a chance to read them.

Give copies to participant

Ask for pseudonym choice

Any questions?

SWITCH ON RECORDER

- I have a little information on the sheet you have already filled in, but to set the scene, could you just spend a few minutes telling me about the treatment you have had for breast cancer?

So, now I'd like to focus on the area of sexuality

- I'd like to begin by asking you to tell me how you felt about your sexuality before your diagnosis?
- Can you tell me how you felt during your treatment (refer back to info already given)?
- Can you tell me how it has been for you since your main treatment ended?

Prompts if required

Remember to give BACP details to participant in case interview has raised issues they would like to explore further.

Explain what happens next – transcript will be sent for comment/approval

## Example of Analysis

Lizzie:

292 that it interferes with the plumbing, er was pretty challenging, and a bit of a  
 293 shock, er and not very nice. And again, to sort of be confronted with that,  
 294 you know, when you're already feeling pretty vulnerable, with no hair, and  
 295 with a guy you haven't seen for a long time

296 I: And something you weren't necessarily expecting, (absolutely) and no-  
 297 one had told you about this, and then

298 L: I was kind of half aware, but I suppose I just hadn't thought about it  
 299 because it hadn't cropped up till now, it was just off my radar, and then  
 300 obviously, it was an issue. But you know, because of the guy, because of  
 301 the relationship we had, it was fine, and we were able to just laugh about  
 302 it, and you know, find a solution, and you know, that's fine. I was very  
 303 lucky with that, that I was with a guy who was like that, you know, who was  
 304 able to just laugh about it, and it not be a big deal. But yeah, it was um,  
 305 yeah all pretty weird, certainly took some of the fun out of it (laughter).  
 306 Yeah, so, yeah, it was a very strange time, and you know, after that, even  
 307 after I was starting to feel like I was getting my identity back, for quite a  
 308 while, you know, the double mastectomy and reconstruction, that was,  
 309 every time I was with a guy, it was kind of this thing, and you had to  
 310 explain, like before you even really, 'cos there's always that worry that  
 311 they're gonna be completely unable to deal with it, and you know, and

being kicked when you're down  
 challenge of chat on top of everything else  
 a shock  
 being kicked when you're down?  
 challenge of chat on top of everything else  
 guy made it ok - able to laugh  
 found a solution (sandy & practical!)  
 lucky to be with him  
 weirdness  
 making things with laughter but...  
 gradual regaining of identity  
 gradual process of reclaiming identity  
 having to disclose early  
 having to go through it over and over with each new guy  
 worry men won't be able to deal with it  
 worry they won't be able to deal with it  
 their problem?

15

Jessica:

168 know how I'd have felt if I'd met someone who'd had it done, you'd  
 169 like to think that I'd have been accepting, but you just don't know do  
 170 you, how you're going to feel about it (no). I don't know.

171 I: So then you met your current partner?

172 Yeah and she's um, she's always been very complimentary about  
 173 it, how, you know, it's beautiful because it you know, it saved me  
 174 almost, because if I hadn't had it done would I be here still? (yes)  
 175 Um, so it's nice and she's given it nicknames and things (laughter).

176 I: It's almost celebrating, (yeah) as something to be, as you say if that  
 177 wasn't there you might not be here, that sort of thing (yeah). There's  
 178 some humour (yeah) in it the way you're describing it.

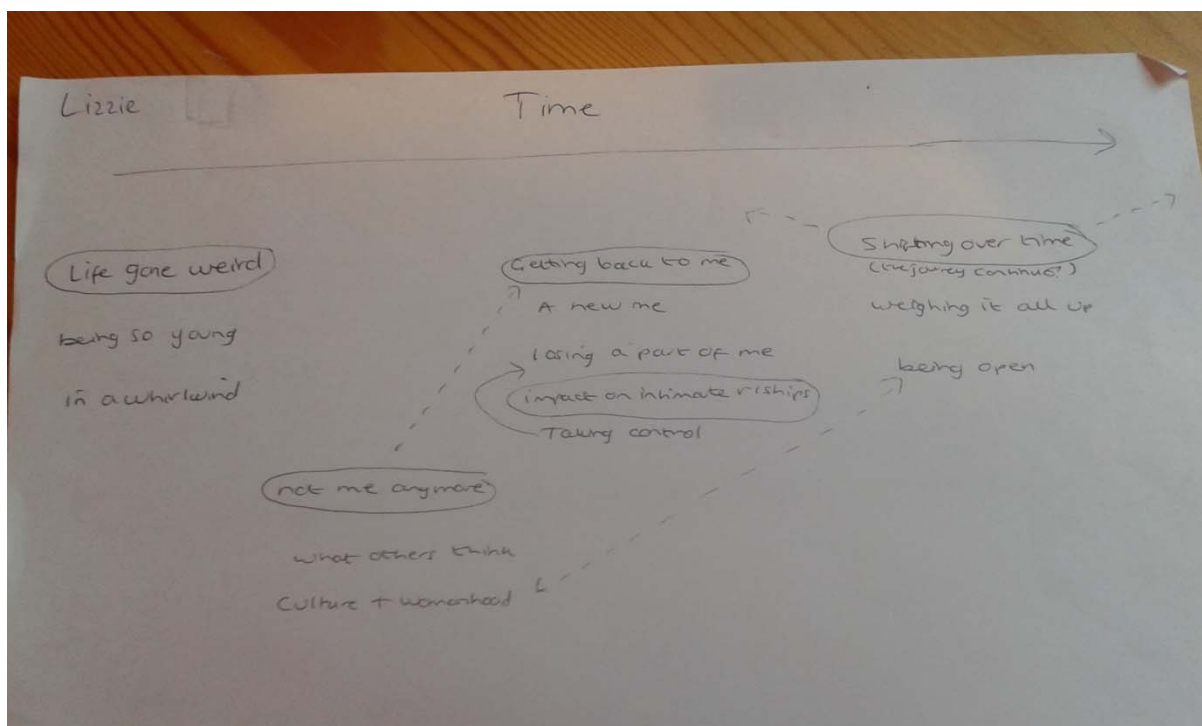
179 J: So yeah, she's very supportive.

180 I: So I think you've already touched on this as well, treatment side  
 181 effects was something I was going to ask about, different drugs can  
 182 obviously effect, physically and psychologically how you feel about  
 183 sex and that sort of thing (mmm), but you were saying, I think, that

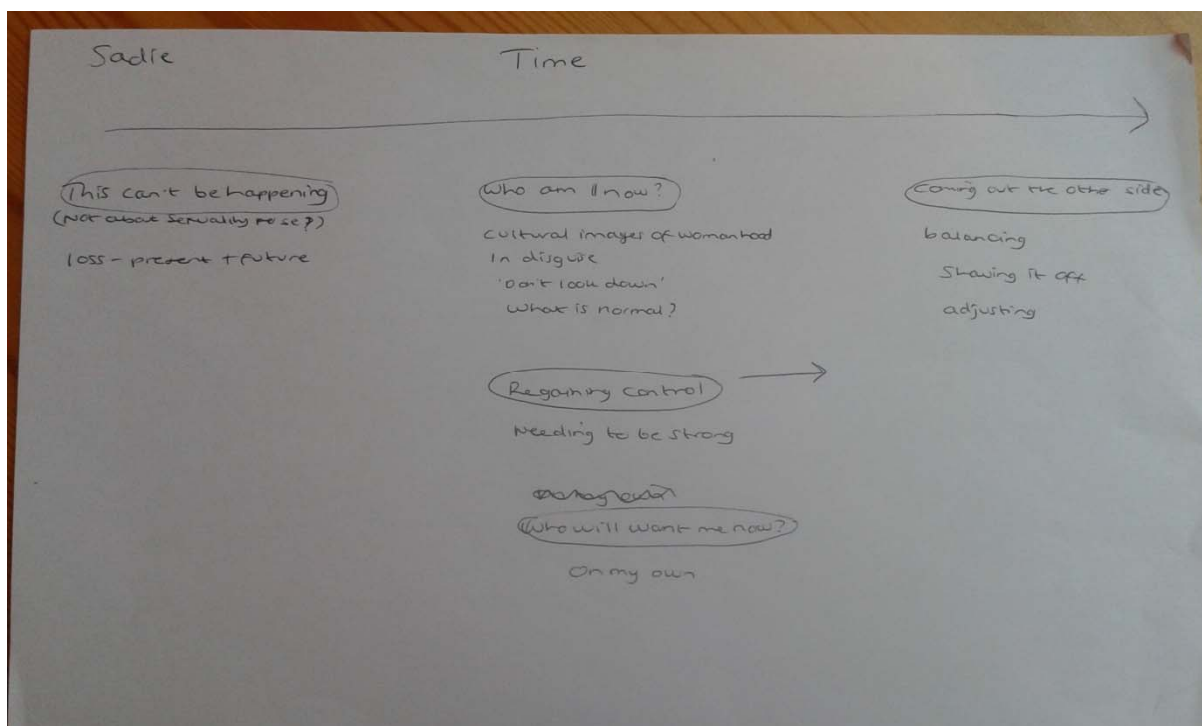
would I accept another?  
 wouldn't I accept it?  
 relative  
 could I accept it in another?  
 current partner - positive impact  
 recognizes significance of it  
 "celebrates" it  
 endowing it with sacred status  
 voice quieter and softer  
 humour, affection  
 mortality  
 support of partner

## Example of Creation of Themes

Lizzie:



Sadie:



## Excerpt from Master Table of Themes and Quotes

| Theme                | Jessica   | Sadie   | Lizzie   | Ceri |
|----------------------|---|---|--|------|
| <b>Who Am I Now?</b> |   |   |  |      |
| Not me anymore       | On the day it happened it's almost like you're going to death row or something (mmmm), obviously you are going to wake up not the same (15/245) | I'm going to look like some freaky kind of alien(8/166) (anticipating hair-loss) But I would probably say it took me about a month to 6 weeks, before I could actually look at myself in the mirror, at my surgery scar (12/243) , I was so worried I think that I'd just look down and I would just break down, and it was kind of, I think part of it was, I've got to be strong, (13/261) I suppose at night, again because it gradually then came off, and I sort of morphed back into that strange looking alien creature that you don't want to look at in the mirror. (21/430) (talking about make-up) | I do remember a sort of very distinct shift in feeling within me, with kind of, of kind of just losing my identity, I think is the thing, 'cos you sort of just don't look like yourself anymore, and you look in the mirror and that person doesn't look like you. (8/148) I just distinctly remember this feeling of having to have a real sense of humour about yourself, and you just couldn't, you couldn't rely on any of that, that just wasn't even in the game (yeah), and so it was like being a completely diff... it was like I'd stepped into someone else's shoes. I didn't feel sexy anymore, I didn't feel like myself anymore... (8/161) So, it's 18 months of not really having an outward identity, certainly that's how I found it (mmm), or not an outward identity that I associated with, |      |

| Theme          | Jessica   | Sadie  | Lizzie  | Ceri  |
|----------------|---|--|---|---|
|                |   |  | and so that was huge for me, (11/207) (hair loss)<br>...at the time, it was almost less challenging than losing my hair, 'cos you could cover it up and you didn't have to be constantly conscious of it, (10/200) mastectomy. Note – Sadie says this too   |   |
| Taking control | Yeah, I guess was quite at the time, thinking about it, I was probably quite obsessed with seeing what they looked like, and I had two people came to the office to see me, so I could have a look and feel. (18/294) | I was always, you know, looking into what was coming up next, and why you lose your hair, and looking into that, and then telling my friends, this is why it works. You know, sort of educating people, but I say the whole, you know I just, I think now, looking back, it's probably, that I thought if I just went aaagh, and just lost it, I don't know if I would have come back from that, so it was like, I need to be ready to sort of deal with that appearance (14/286)<br>So, I had my two wigs, and I think it was two days before I started my chemo, um, I asked my hairdresser to cut all my hair off. (16/330) | ...the minute I realised I was going to lose my hair, that's the thing that pushed me over the edge (10/189)<br>...having cancer was manageable if I could at least just hide it, you know, if I could just carry on being me.....(10/195)<br>I went to that 18 month mark, and thought sod it, I'm just going to dye it blonde, and I dyed it blonde, and immediately it was like a shift, and ..... and I had it cut...into a bit more of a funky style.....and then that summer, I think that was the start of when I just started to feel sort of like myself again, (11/225) | I had a wig (you had a wig), but I found that too uncomfortable, so it was just scarves really<br>I: Right, ok, and how did you feel when you were wearing those?<br>C: Um, initially it was like all a shock, but I just got on with it, and I didn't think about it; does that make sense? (mmm, yeah). I sort of blanked it off. And having my nephews, ah the one picture was so funny, he did draw a picture of me with my bandana on, and putting washing on the line, and it had like a big bow on the back and he said, oh, that's auntie XXXXX that is (laughter), so, but I think having nieces and nephews around, that helped |



| Theme | Jessica | Sadie  | Lizzie | Ceri     |
|-------|---------|--|--------|----------|
|       |         | <p>....I just had my head over the bath, just like rubbed my hair and it was just falling out, 'cos I didn't want that whole, having long hair and then that, you know, that's like something out of a horror movie isn't it .... I think the last few bits, I just sort of shaved off 'cos I thought I just need to get rid of it, (17/359)</p> <p>it was almost like that transformation of, right, put on the make-up, put on the wig, dress up, put on the killer heels, matching handbag, and go and rock that hospital room out,(20/423)</p> |        | (15/288) |

## Definitions

***Axillary node clearance*** – the removal of the lymph nodes (sometimes called lymph glands) from the armpit

***Chemotherapy***– the treatment of disease by the use of chemical substances, especially the treatment of cancer by cytotoxic and other drugs

***DIEP reconstruction*** – A flap of fat and skin (but not muscle) is taken from the abdomen to create the shape of a breast. The tissue and its blood vessels are completely detached from the abdomen and reconnected to a new blood supply in the chest area.

***Herceptin*** – a drug that works by blocking the effects of the HER2 protein, which is found at unusually high levels in HER2-positive cancers. It also encourages the immune system to attack abnormal cells

***Hormone Therapy*** – Some types of breast cancer are fuelled by the presence of oestrogen in the body, and a variety of drugs are used to lower levels:

***Tamoxifen*** – a drug that blocks the oestrogen receptors on cancer cells, used in the treatment of breast cancer.

***Letrozole*** – a drug that works by stopping the conversion of androgens into oestrogen and so reduces the amount of oestrogen circulating in the body

***Zoladex*** – a drug that works by suppressing the production of testosterone and oestrogen.

***Hysterectomy*** - a surgical operation to remove all or part of the womb.

***Implant reconstruction*** – Two main types of implant are available. They are both made of a silicone rubber envelope. One is filled with silicone gel and the other with sterile salt water (saline). Implant surgery is the simplest way of making a new breast. It causes very little scarring but the breast will not feel as natural as it would if made with living tissue.

**Lumpectomy** – a surgical operation in which a lump is removed from the breast, typically when cancer is present but has not spread

**Mastectomy** – a surgical operation to remove a breast

**Nipple reconstruction** – there are two main types: 1. nipple flap – the surgeon folds skin on to the new breast into a nipple shape and 2. nipple-sharing graft – the surgeon takes part of the nipple from the natural breast and places it on the new breast.

**Nipple tattoo** – Once a new nipple shape is in place, the new nipple and area around it are tattooed to match the colour of the nipple and areola of the natural breast.

**Radiotherapy** – the use of high-energy rays, usually x-rays and similar rays (such as electrons) to treat disease. It works by destroying cancer cells in the area that is treated.

**Strattice** – a specially processed pig skin. These are sheets of tissue that create a layer to hold the breast implant firmly in place

**Participant Biographies**

**Jessica**

Jessica is 35 and was diagnosed with breast cancer 3 years ago.

Her treatment included a lumpectomy, followed by a mastectomy and axillary clearance, a strattice reconstruction with expander implant, followed by a swap to a silicone implant and nipple reconstruction and tattoo. She is currently taking Tamoxifen. Eggs were harvested and frozen, as a precaution prior to beginning this.

Jessica was in long-term partnership at diagnosis; this ended during treatment. She was then single for several months and is now in a committed relationship.

**Sadie**

Sadie is 40 and was diagnosed with breast cancer 5.5 years ago.

Her treatment included a mastectomy, axillary clearance, chemotherapy, radiotherapy, Herceptin and a DIEP reconstruction. She is currently taking Tamoxifen.

Sadie was single at diagnosis and remains so.

**Lizzie**

Lizzie is 30 and was diagnosed with breast cancer 6.5 years ago.

Her treatment included a double mastectomy (one side was preventative), implant reconstruction, chemotherapy and Herceptin.

Lizzie was in a casual relationship at diagnosis, single for 18 months and has been in a committed relationship for 4 years.

**Ceri**

Ceri is 44 and was diagnosed with breast cancer 5.5 years ago.

Her treatment included a lumpectomy, axillary clearance, chemotherapy, radiotherapy, Herceptin, Tamoxifen, Letrozole, Zoladex, full hysterectomy (due to thickening of womb caused by Tamoxifen)

Ceri was single at diagnosis; at the end of treatment a friendship became a partnership, and this continues.